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AUTHOR Kramer, Joel
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ABSTRACT

The prevalence of dementias in the elderly is steadily increasing. While caring for a dementing patient at home, families are subject to tremendous physical stresses and emotional reactions such as guilt, anger, grief, role confusion, depression, resentment, and loneliness. Two group treatment models addressing the mental health needs of caregivers are discussed in this paper. The Education/Support group is an ongoing, informal environment where problem solving, supportive interchange, and information sharing occur. Participants are able to express and normalize feelings, develop a peer support system, and learn more about dementias, community resources, legal alternatives, and caregiving techniques. The Family Therapy group is smaller, time-limited, and focuses more on helping members make personal adaptations to their role as caregiver. The group works toward a better understanding of feelings and coping styles with the objective of implementing some change in the caregiver's behavior, attitudes, or feelings. Recommendations are made for research and for additional caregiver support. (Author)

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TREATING FAMILIES OF DEMENTED PATIENTS:

TWO GROUP MODELS

Joel Kramer
Martinez VA Medical Center

Mailing Address: Joel Kramer, Psy.D.
Psychology Service (116B)
VA Medical Center
Martinez, CA 94553
(415) 228-6800, Ext. 302

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The prevalence of dementias in the elderly is steadily increasing. While caring for a dementing patient at home, families are subject to tremendous physical stresses and emotional reactions such as guilt, anger, grief, role confusion, depression, resentment, and loneliness. Two group treatment models addressing the mental health needs of caregivers are discussed. The Education/Support group is an ongoing, informal environment where problem solving, supportive interchange and information sharing occur. Participants are able to express and normalize feelings, develop a peer support system, and learn more about dementias, community resources, legal alternatives and caregiving techniques. The Family Therapy group is smaller, time-limited, and focuses more on helping members make personal adaptations to their role as caregiver. The group works toward a better understanding of feelings and coping styles with the objective of implementing some change in the caregiver's behavior, attitudes or feelings. Recommendations are made for research and for additional caregiver support.

The prevalence of dementias in Americans over 65 is estimated to be 5% and increases to as high as 15% for persons over the age of 80. There are currently just under one million geriatric patients suffering from significant loss of intellectual functioning which impairs their capacity for independent living. Etiologies include multi-infarct states, cerebral vascular accidents, and primary degenerative disorders such as Alzheimer's Disease. The incidence of dementia is expected to increase dramatically in upcoming decades, with an estimated 1.2 million demented patients requiring care at a staggering cost by the year 2000 (Ban, 1977).

Caring for demented patients represents a growing challenge to the nation's medical and social support systems. Cognitive impairment is the leading cause of institutionalization for the elderly. Annual costs run about six billion dollars (Coyle, Price and DeLong, 1982), costs which are borne primarily by families and government (insurance carriers typically do not provide for the care of the chronically ill). Family members currently care for the majority of demented patients at home and will continue to be a principle means of care provision for at least three reasons. First, strong familial ties motivate families to remain united for as long as possible. Second, the overwhelming cost of institutionalization restricts the availability of quality institutional care to all but the most affluent of families. Third, there is a shortage of available beds for demented patients. Many skilled nursing facilities (SNFs), in fact, are not equipped to handle physically active but disoriented, memory impaired patients who may wander, act out aggressively or be incontinent. The quality of care at facilities that do accept demented patients is also of concern to family members. Many families strongly believe that SNFs will not provide the

stimulation, safety and affection that exists at home. A tremendous number of families, then, are attempting to care for a demented patient for as long as possible; for many patients, home care can extend beyond a decade.

The physical and emotional burdens of caring for a demented person can be devastating. Even in the early stages of a progressive dementia, major changes occur in the patient and in the family system. Formerly competent adults gradually lose their ability to perform simple every-day tasks like dressing, setting the table or driving. The quantity and quality of communication decreases as the patient develops word-finding difficulties, concrete thinking and memory impairment. Poor judgement, insensitivity and forgetfulness lead to a variety of irritating behaviors such as angry outbursts, endless repetition of questions, and wandering, while the delusions and hallucinations experienced by many severely demented patients can be frightening to patient and caregivers alike. Free time becomes a rare luxury as the patient requires constant monitoring and assistance. Many spouses who themselves are elderly and experiencing health problems struggle with the physical demands of caregiving.

Family and social system changes further add to the strains of caregiving. Families must contend with the costs of medical and nursing care often in conjunction with lost income after the patient and caregivers leave regular employment. Roles change as the dementia victim acts less like a parent or spouse and more like a child requiring constant care. As more time is spent caregiving and the patient's impairments become more apparent, families experience social isolation. Strains within a family concerning who will assume responsibility for which tasks are commonplace.

Even under optimal environmental conditions, caring for a dementing

patient can be very painful emotionally. Family members commonly report intense anger, denial, embarrassment, resentment, depression and anxiety. They fear that these emotional reactions are unjust or inappropriate and experience tremendous amounts of guilt.

The mental health needs of this growing population of caregivers are gradually being recognized. There are now monthly meetings in many communities where members share information about local resources, learn about new research and legislation, discuss patient management issues, and develop a network of supportive peers. These groups have succeeded in meeting the needs of many participants. Large numbers of caregivers, however, experience sufficient emotional stress to warrant more intensive, professionally led groups. Two alternate models for such groups, the Education/Support group and the Family Therapy group, are discussed in terms of the client needs they address and how they are structured. The descriptions are based on the author's experience with such groups.

The Education/Support group is designed to provide an ongoing, informal environment where problem-solving, supportive interchange and information sharing can occur. Optimally, such groups meet weekly for one and a half to two hours, with group size ranging from eight to fifteen members. The group is open-entry/open-exit and allows members to come as regularly as they need and/or are able. Caregivers are typically an even mix of spouses and children; their family members suffer varying degrees of cognitive impairment resulting from a range of disease states (most typically Alzheimer's Disease).

The inclusion of patients in the group has distinct advantages and disadvantages. One virtue of their participation is that the caregiver does

not have to make alternate arrangements for the patient's care. More importantly, mildly demented patients make valuable contributions by describing (to the best of their ability) their perspective and feelings about the patient role. On the negative side, some caregivers feel that they can speak more freely without the patient present. Others are grateful for the respite from caregiving that the group affords.

A major task of the Education/Support group is to help members feel they are not alone and to enable them to learn from the experience of others. The discussions focus on the participants *in their role as caregiver*, i.e. the problems they encounter and the emotions they experience as they care for a demented spouse or parent. It affords them an opportunity to describe their anger and frustration with an impersonal neurologist, dispair over how a husband can no longer pour his own milk, frustration with a mother who refuses to bathe, guilt about losing their temper, concern about a wife's hallucinations, and hope that tomorrow will be easier than yesterday. Certain underlying themes emerge regularly: 1) It is normal to experience negative emotions. Caring for a demented patient is demanding, stressful and requires considerable adjustments in the life of the caregiver. Feelings such as resentment, anger, hostility, depression, impatience, and even hopes for the patient's early death are commonplace and acceptable; 2) It is normal to make mistakes. There is much about caregiving that is random and out of one's control. The most one can do is to act in good faith and try one's best. No one is perfect and it is unrealistic for caregivers to expect themselves to be exceptions to that rule; 3) It is important to accept the disease and its consequences and not harbor unrealistic hopes. Hopes and expectations of miracle cures, mistaken

diagnoses and wonder drugs lead to painful letdowns which are emotionally disruptive; 4) It is necessary to give one's own needs top priority at times. Many caregivers become enslaved to their family member's needs and demands, feeling that they must be "on duty" 24 hours per day and sacrificing in the process their own interests, relationships and goals. Basic human needs for privacy, rest, and friendships often go unfulfilled, resulting in isolation, fatigue, resentment and less effective caregiving; 5) Caregivers do not need to take the patient's behaviors personally. The patient has a brain disease which causes them to strike out angrily, make accusations, act lethargically, or behave strangely. It is not the caregiver's fault and assuming responsibility only succeeds in elevating the caregiver's level of stress.

> Edie's mother had deteriorated to the point where she was occasionally incontinent, began wandering, woke up frequently during the night, and oftentimes did not recognize Edie. Edie was exhausted, had begun missing work, and felt at the end of her rope. She had considered placing her mother in a skilled nursing facility but felt too guilty and too overwhelmed to begin looking for an adequate placement. The group helped Edie recognize that her mother was past the point of appreciating her efforts or even knowing where she was, and that a SNF could provide better care than an exhausted Edie. They encouraged Edie to resume her own personal life, recommended two or three facilities and suggested she contact her brother to assist with the move. Edie followed through with the suggestions.

> Steve's wife would create a fuss whenever he attempted to take her anywhere. In discussing his situation, it became apparent that after 35 years of sharing decision-making with his wife, Steve was reluctant to unilaterally direct her activities. The group commented that his wife was probably responding to the tentativeness in his voice when he suggested they go someplace. They encouraged Steve to accept that his role now was to be in charge and recommended that he firmly announce when it was time to go out. Steve tried that and reported significant improvement in his wife's responsiveness.

The Education/Support group also serves as an important source of information about dementias. Frequently, group members are new to the role of

caregiver and are confused about the nature of their patient's illness, diagnostic procedures, prognosis, predictable behavior and personality changes, legal and financial issues, and available community assistance. Caregivers also express a strong interest in better understanding the psychotropic medications commonly prescribed and seek guidance on how to have their needs best met by the medical community. Guest speakers can be scheduled periodically to discuss special topics such as Social Security benefits, protecting assets, obtaining power of attorney, stress management, relevant legislation, medications, behavior management techniques and research trends.

The group leader's tasks are to maintain an open-ended discussion and foster a sense of interpersonal safety. The explicit contract is for support and information; therefore, it is important that members feel comfortable expressing feelings without fear that they must disclose their darkest secrets or be "psychoanalyzed". Once trust is established, caregivers readily assume responsibility for bringing up material for discussion. An important outgrowth of the groups is that members acquire a support system. Toward this end it is helpful for members to sit in a circle and talk directly to one another rather than through the leader. A short break also facilitates socializing amongst members. Other central tasks for the leader are to maintain the group focus at a problem-solving and feeling level, foster a sense of communality, elicit support and feedback, provide information about dementias, and make referrals for those who may need additional medical consultation or a more intensive therapeutic experience.

One device for more specialized counseling is the Family Therapy group. The Family Therapy group is smaller (6-10 members), of limited duration (6-

10 weeks) and is for those caregivers who identify needs that an Education/Support group cannot meet. Group members typically have as a goal some change in their attitudes, beliefs or behavior; thus the group is explicitly centered more on the caregiver *as a person* than on patient care or the role of caregiving. The group has a fixed membership and, as with most therapy groups, prospective members should meet with the therapist prior to the first session for clarification of goals and orientation to the process of therapy. Members are typically individuals who are experiencing excessive stress or whose coping styles, while adequate for most situations, are not working well in the caregiving situation. Common issues include fear of being unable to cope, depression, poorly controlled anxiety, loss of personal identity, guilt feelings, intense grief, and difficulty adapting to their changed (and changing) world. Examples of behavioral traits that often prove counterproductive are shyness, unassertiveness, passive-dependence, self-pity, projection of responsibility, rigidity, and enmeshment.

> Jenny felt abandoned by her family and friends since her moderately demented husband first became ill. She expressed considerable resentment toward them and envied other caregivers who seemed "luckier". In group she needed considerable encouragement to describe her more vulnerable feelings of loneliness and depression. It emerged that she had always felt insecure about her acceptability to others and protected herself by being defensive and non-disclosing. The relationship between her interpersonal style and her isolation was pointed out. It was also observed that as Jenny spoke more openly about her feelings, others in the group felt closer and more responsive, thus illustrating to her how she might create a more supportive social network.
>
> Milt and his demented wife were both in their late 70's. He came to group complaining bitterly of her poor hygiene and passive-aggressive behaviors and requested guidance on how to change her. It became clear that Milt created a good many of their struggles by being inflexible about his expectations and that hygiene was a focal point for his anger. Milt intensely resented the impositions his wife's illness created and wished "she was out

of the way". His hostile feelings, her deterioration and her poor hygiene all clashed with his lifelong penchant for having things "the way they're supposed to be". The greater his guilt and inner turmoil, the more inflexible he became and the more the situation worsened. Intervention consisted of helping him accept his negative feelings as normal, pointing out how his usual coping style was not proving successful, and suggesting alternatives.

Responsibility for content lies primarily with the members in a Family Therapy group. The therapist plays the critical role of helping caregivers, many of whom are not psychologically minded, master the uncomfortable process of self-examination and disclosure. Without direction, groups tend to skip lightly over sensitive areas and drift onto safer, more superficial topics. Thus the leader must remain active focusing the group's attention, offering insights and placing responsibility for change with the caregiver. The ambience, while allowing for confrontation, should be predominantly supportive and accepting.

Despite the obvious differences in the goals, structure and process between the Education/Support and Family Therapy groups, a number of important similarities exist. First, most members will be women, with wives and daughters about evenly represented. The reasons for this are not clear. It may be that the caregiving role is most often assigned to the women in the family, or that women are more willing to request emotional support. A second similarity is that a great many families in need of support are unable to participate because of their caregiving obligations. This is especially true when the patient cannot be left alone for any length of time and outside assistance is not available or affordable. The need for low cost home health care aides, respite centers, brief care facilities and self-help networks is paramount. Finally, most participants view themselves as adequately functioning adults who are forced to cope with a tragic situation. They are seeking an opportunity to ventilate, encouragement, and

acceptance; they need to hear that they are doing all right, not just what they should do differently.

The precise way in which a counselor conducts groups with the families of demented patients will vary according to his/her theoretical orientation and clinical training. The two models described above are offered as examples of approaches which have proven viable. The number of groups designed to address caregivers' needs appears to be growing rapidly as mental health professionals and the general public become more knowledgeable about the dementias. It is hoped that the Education/Support and Family Therapy models can serve as guides for newly created groups.

Research into the efficacy of such groups is also important. Data are currently being collected in the San Francisco Bay Area on the effect therapy groups have on stress levels and psychological well-being. Studies delineating the nature of the caregivers' stress and needs can also help in designing and implementing group treatments.

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